

Stakeholder Survey Data Points for HB1493 Report

Key Takeaways from Stakeholder Survey

Accessing Services and Supports

- Most individuals access information on services and supports through friends/family members (41.7%) and through their doctor's office (28.9%) regardless of if they are currently receiving services or not. Survey respondents who currently receive services also noted accessing information through their case managers (43.3%).
- One-third (29.8%) of individuals currently receiving services noted that it is somewhat difficult or very difficult to find the information they need to get appropriate care and supports.
- Caregivers and individuals not currently receiving services noted that they would most likely learn about services through family/friends (41.6%), their local AAA (37.0%) or through the internet (23.6%). Notably, only 17.0% of individuals not receiving services noted they would learn about services through their local ADRC. Given that ADRCs are meant to be the access point for LTSS in the state, there may be a lack of awareness of the distinction between AAAs and ADRCs among individuals not currently receiving services.

Coordinating Services and Supports

- Over 45% of caregivers noted it was somewhat or very difficult to coordinate care across all of the health care professionals or providers who supported or provided care to their loved ones.
- The majority (58.2%) of case managers shared that the typical caseload for a full-time case manager is more than 61 individuals and 46.5% noted that the number of individuals on their case load do not give them the time to meet the needs of the individuals they serve.
- Case managers felt that the strongest aspect of the current HCBS system is that the system is focused on individuals' needs and preferences (53.5%). However, an opportunity for improvement in the current system is increasing workforce availability, training, and quality.

Provider Capacity and Workforce Challenges

- Almost all case managers (92.9%) and the majority of providers (62.5%) cited the need for more direct care staff as an opportunity for improvement in the state's HCBS system. Case managers (78.2%) and providers to a lesser extent (46.4%) also cited the need for more professional staff (e.g. nurses, social workers, therapists) as an opportunity for improvement. Both case managers and providers cited more generally that the lack of providers is one of the biggest barriers that prevent individuals from receiving the services they need.
- HCBS providers felt that the strongest aspects of the current HCBS provider system that ensure high quality services and supports include an effective incident reporting mechanism (55.4%), sufficient scope (53.6%) and duration (51.8%) of services provided, and sufficient provider qualifications outlined in code (50.0%). However, providers felt that the existing reimbursement structure is not sufficient to ensure high quality services (72.3%) and to provide supports at the right time and in the right place (68.8%).

Person-Centered Services and Supports

Choice and Control

- Two-thirds (66.6%) of survey respondents live in their own homes or apartments and an overwhelming majority (94.9%) felt that remaining in their own home as they age was very important to them. Of the remaining one-third of survey respondents currently living with other family, in an assisted living facility, or in another long-term care setting, the majority (58.6%) were happy with where they lived.

Unmet Service Needs

- The majority (86.9%) of survey respondents currently receiving services noted that their services meet all or some of their needs.
- Among individuals currently receiving services who noted they had unmet service needs, the most common service requested was homemaker/chore services and transportation to medical and non-medical appointments.
- Both providers and case managers also emphasized the need for transportation to non-medical activities as well as additional mental health supports.

Caregiver Supports

- Most caregivers provide a wide range of supports to their loved ones. The most common supports caregivers provide are taking them shopping or shopping for them, providing transportation to medical appointments, providing social activities or companionship, and helping with household chores.
- The majority of caregivers (70.5%) felt prepared to help their loved ones. Similarly, 78.8% of individuals currently receiving services noted that their family members or friends were also prepared in helping them with their daily activities.
- Professionals who regularly interact with caregivers (doctors/nurses/social workers) are more likely to ask if caregivers need help to take care of loved ones as opposed to if they need help to take care of themselves.

Meeting Future Needs

- Individuals not currently receiving services would prefer to have care provided at home by both family/friends and a paid helper in the future (32.7%). 30.5% of individuals not currently receiving services noted that they would not move to a nursing facility.
- Almost 30% of individuals not currently receiving services felt that it would be very likely that they would be providing caregiving assistance to a loved one in the future.
- When compared to non-caregivers, caregivers were more likely to think that they would require assistance with ADLs and IADLs in the next two years and the majority (55.7%) of caregivers would prefer to have care provided at home both with informal and formal supports.
- Nearly half (48.1%) of caregiver survey respondents thought they might need respite care or caregiver supports in the future, compared to less than one-fifth (18.1%) of non-caregivers. Other services caregivers thought they might need in the future include family/caregiver training, homemaker/chore services, transportation to get to medical appointments, and therapy services.

- The majority (57.0%) of individuals not currently receiving services (both caregivers and non-caregivers) are very concerned that they may not be able to afford long-term services and supports for themselves and their families in the future.

Selection of Open-Ended Responses

- “They never asked me my opinion nor did they ever think of caregiver burnout.” – Caregiver
- “Due to my education (social worker) & expertise I was able to adequately seek supports & services for my family member. Majority of people DO NOT have this knowledge & are very limited, frustrated in obtaining services.” – Caregiver
- “It is INCREDIBLY difficult to get services. Case managers have been of no help. I have gotten very little information and no support to find the services my loved one needs. My family has struggled significantly because we have not gotten the supports and services we need. I do not know how to file a complaint about a case manager or how to find appropriate case management. Since the AAA is my case manager (I was given no choice and only recently found out I can change case managers but don't know how), who do I go to when they are the problem but they are also supposed to be doing the oversight to ensure services?” – Caregiver
- “No one offers help. You have to demand it. And it's substandard and NOT how YOU'D care for your loved one yourself. It's begging for help and it's wrong.” – Caregiver
- “The reimbursement rate for home care nurses is so low that my daughter never has the staff she needs. We have respite hours that we cannot use because it needs to be an lpn or rn. We are worn out and tired. My child is 14 and should be on a waiver designed for children but Indiana does not have one.” – Caregiver [this quote could be helpful for the section where we describe the need for a separate children's waiver]
- “It is hard to know where to start when considering the need for care giving. We get invitations all the time to attend presentations about financial planning for aging. Are there public presentations about planning for care-giving and other needs of aging in place?” – Individual Not Receiving Services
- “It is SOOO hard to meet the needs of clients with mental health or developmental disabilities. They don't fit nice and neat in the box for aging services, but they often qualify.” – Case Manager
- “Finding providers (especially skilled) to meet the needs or [sic] our caseload. We have a lot of clients on our caseload that don't have services because we cannot find providers to meet the service needs.” – Case Manager
- “Most caregivers do not have the knowledge of resources available for them and their loved one, and with the high turn-over of case managers, the caregiver does not have a close relationship with them, as the Case manager changes often.” – HCBS Provider
- “The area that is the biggest barrier is the lack of knowledge of available services. This also leads into the access and difficulties with the eligibility process. It is a complex and sometime convoluted process for our families. Families don't care about the titles of the waivers they just want to find someone help with the immense responsibility of caring for another person” – HCBS Provider